

TOWSON UNIVERSITY  
COLLEGE OF GRADUATE STUDIES AND RESEARCH

POST-LINGUALLY DEAFENED ADULTS, COCHLEAR IMPLANTS AND  
QUALITY OF LIFE (QoL): A RESEARCH STUDY

by

Nancy E. Shaw Hart

A Thesis

Presented to the faculty of the Department of Audiology,  
Speech-Language Pathology, and Deaf Studies, Towson University

in partial fulfillment of the requirements for the degree

Doctor of Audiology

June, 2005

Towson University

Towson, Maryland 21252

© 2005 By Nancy E. Shaw Hart  
All Rights Reserved

**TOWSON UNIVERSITY  
COLLEGE OF GRADUATE STUDIES AND RESEARCH**

**AUDIOLOGY DOCTORAL THESIS APPROVAL PAGE**

This is to certify that the thesis prepared by Nancy E. Shaw Hart, entitled Post-Lingually Deafened Adults, Cochlear Implants and Quality of Life (QoL): A Research Study, has been approved by this committee as satisfactory completion of the thesis requirement for the degree of Doctor of Audiology (Au.D.).

Chair, Thesis Committee

<hr style="border: none; border-top: 1px solid black;"/>	<u>Brandt Culpepper</u>	<hr style="border: none; border-top: 1px solid black;"/>
Signature	Typed Name	Date

Committee Member

<hr style="border: none; border-top: 1px solid black;"/>	<u>Peggy Korczak</u>	<hr style="border: none; border-top: 1px solid black;"/>
Signature	Typed Name	Date

Committee Member

<hr style="border: none; border-top: 1px solid black;"/>	<u>Regina Presley</u>	<hr style="border: none; border-top: 1px solid black;"/>
Signature	Typed Name	Date

Dean, College of Graduate Studies and Research

<hr style="border: none; border-top: 1px solid black;"/>	<u>Jin Gong</u>	<hr style="border: none; border-top: 1px solid black;"/>
Signature	Typed Name	Date

## ACKNOWLEDGEMENTS

With sincere thanks to Ms. Mary Koch for introducing me to the world of cochlear implants; Dr. Regina Presley, Committee Member, for sustained encouragement of and devotion to this project; Dr. Sharon Glennen for teaching me how to be a responsible consumer of research and a better academic writer; Dr. Peggy Korczak, Committee Member, for valuable editorial input; and Dr. Brandt Culpepper, my Committee Chair, for her sustained enthusiasm and continuous, superb guidance spanning several years. I would also like to acknowledge the unconditional support of my husband, Lloyd, and my daughter, Abby.

ABSTRACT

POST-LINGUALLY DEAFENED ADULTS, COCHLEAR IMPLANTS  
AND QUALITY OF LIFE (QoL): A RESEARCH STUDY

By

Nancy E. Shaw Hart

Hearing loss is the third most common chronic medical condition in the elderly. Treatment options for hearing loss include hearing aids and cochlear implants. Cochlear implants (CI) are a viable option for post-lingually deafened adults, although benefit is extremely variable from person to person. Assessing quality of life (QoL) as a way to document CI benefit can be helpful both clinically and with strategic planning for centers. While functional benefit assessment methods are standardized, there is no standard protocol for assessing QoL. Results from this study suggested that a standardized protocol for assessing QoL with post-lingually deafened adults using cochlear implants could be helpful.

## TABLE OF CONTENTS

List of tables	vii
List of figures	viii
Introduction	1
Review of literature	
I. Cochlear Implant Overview	4
II. Post-Lingually Deafened Adults	6
III. Quality of Life	7
IV. Post-Lingual Deafness and QoL	8
V. The Importance of Assessing QoL	10
VI. How QoL is Assessed	13
VII. How Cochlear Implants Affect QoL	16
VIII. How QoL Assessment Can Be Helpful Clinically	17
IX. How QoL Assessment Can Be Helpful with Strategic Planning for Cochlear Implant Centers	19
Purpose of Study	21
Methodology	22
Results	26
Discussion	36
Appendices	
Appendix A: IRB Approval	43
Appendix B: Questionnaire	45
Appendix C: Follow-up Interview Questions	47
Appendix D: Letter of Introduction	50
Appendix E: Letter of Informed Consent	52
References	55
Curriculum Vita	64

## LIST OF TABLES

Table 1: Questionnaire Data From the 6 Centers Assessing QoL	28
Table 2: Areas of QoL Assessed by 6 Cochlear Implant Centers	31

## LIST OF FIGURES

Figure 1: Flow Chart	25
Figure 2: Methods Used to Assess QoL	29
Figure 3: How QoL Data is Used	33
Figure 4: Efficacy Data	34



## Introduction

Hearing loss is the third most common chronic medical condition in the elderly (Weinstein, 2000). In the past several decades there have been significant advances in the technologies used to treat hearing loss. The three main technologies used to treat hearing loss are assistive listening devices, hearing aids and cochlear implants. Despite the recent advances in hearing aid technology, not all people with severe-to-profound hearing loss benefit from hearing aids (Labadie, Carrasco, Gilmer & Pillsbury, 2000). Some of these individuals proceed with cochlear implants. The benefit derived from cochlear implants is also extremely variable from person to person depending on such factors as age at onset of deafness, length of deafness, age at time of cochlear implantation and length of implant use (Cohen, Labadie, Dietrich & Haynes, 2004; Knutson, Murray, Husarek, Westerhouse, Woodworth, Gantz, et al., 1998; Zwolan, Kileny & Telian, 1996).

One factor influencing the reported variability in cochlear implant benefit is that the benefit an individual receives from a cochlear implant can be measured in several ways. One way cochlear implant benefit is assessed is functional benefit, measured by improvement in audiometric and speech testing pre and post cochlear implantation. Functional benefit is well documented for people with cochlear implants (Buchman & Fucci, 1999; Cooper, 1991; Francis, Chee, Yeagle, Cheng & Niparko, 2002; Harris, Anderson & Novak, 1995; Hawthorne & Hogan, 2002; Karinen, Sorri, Valimaa, Huttunen & Lopponen, 2001; Knutson et al., 1998; Zwolan et al., 1996). The level of improvement in these audiometric and speech testing scores of people with cochlear implants is extremely variable due to many of the factors mentioned above. Quality of

life (QoL) benefit, measured by questionnaire and/or interview, is emerging as another method of assessing cochlear implant benefit. Although QoL assessment is well established as a method used to measure outcomes in other healthcare areas, such as cardiology and oncology, it has not been used as a routine assessment tool for the adult cochlear implant population. Recently, there is a growing body of research which supports the benefit of documenting QoL improvements from cochlear implants (Bichey, Hoversland, Wynne & Miyamoto, 2002; Cohen et al., 2004; Djalilian, Smith, King, & Levine, 2002; Faber & Grontved, 2000; Fayers & Machin, 2000; Hinderink, Krabbe & van den Broek, 2000; Mo, Harris & Lindbaek, 2004; United Kingdom Cochlear Implant Study Group, 2004).

While protocols for audiometric and speech testing are standardized and agreed upon, QoL assessment varies widely and there are no standard protocols (Francis, Chee, Yeagle, Cheng & Niparko, 2002; Fayers & Machin, 2000). Consequently, the resulting QoL data are extremely variable. Furthermore, one person may have been able to use the telephone successfully after receiving a cochlear implant and another person may only have experienced an increase in lipreading ability. To further demonstrate the extreme variability in this population, the person with improved lipreading ability may have reported a higher increase in QoL than the person now able to use a telephone. Even though the QoL assessment protocols and resulting data are variable, there is a growing body of domestic and international research documenting the benefits of collecting QoL data with post-lingually deafened adults.

The purpose of this study was to explore the topics of QoL assessment, post-lingual deafness and cochlear implants by polling centers on the East Coast of the United

States to discover to what extent this information was being used in domestic clinical practice.

## Review of Literature

### I. Cochlear Implant Overview

A cochlear implant is an electronic device comprised of external and internal (surgically implanted) parts designed to stimulate intact auditory neurons in people with severe to profound sensorineural hearing loss (House & Berliner, 1991). Currently, there are three main manufacturers of cochlear implants with U.S. Food and Drug Administration (FDA) approval: Advanced Bionics Corporation headquartered in the United States, Cochlear Limited headquartered in Australia, and Med-El Corporation headquartered in Austria (U.S. Food and Drug Administration, 2004). Although each manufacturer has its own unique processing algorithms, most cochlear implants share common design features (Advanced Bionics Corporation, 2005; Cochlear Limited, 2005; Med-El Corporation, 2005). For example, sound energy is picked up by a microphone and sent to a speech processor for modification. Once the sound energy has been modified, it is transferred to an external transmitter. The external transmitter uses radio waves to send the modified sound energy internally. Up to this point all of the components are external. The microphone and processor are frequently worn at ear level, although processors can be connected via hard wire to a body-worn pack. The external transmitter is held in place at the mastoid level by sub-cutaneous magnets.

The internal processing of cochlear implants also involves several steps (Advanced Bionics Corporation, 2005; Cochlear Limited, 2005; House & Berliner, 1991; Med-El Corporation, 2005; U.S. Food and Drug Administration; 2004). An internal implant, adjacent to the sub-cutaneous magnets, modifies the sound energy again. The

sound energy is then sent along minute wires to the electrode array which has been inserted into the scala tympani of the cochlea. The individual electrodes along the array electrically stimulate the remaining intact auditory neurons. The active electrodes also require ground electrodes to be a complete electrical circuit. This electrical stimulation results in the experience of sound approximating the acoustic properties of the original sound energy picked up by the external microphone.

A variety of features of the cochlear implant can be manipulated both internally and externally in an attempt to replicate the acoustic properties of the original sound energy (Advanced Bionics Corporation, 2005; Cochlear Limited, 2005; House & Berliner, 1991; Med-El Corporation, 2005; U.S. Food and Drug Administration; 2004). For instance, the external components can be manipulated to change speech processing strategies, the number of potential channels and input dynamic range. Each of these changes affects the way in which the sound energy is modified. Internally, the number of electrodes, the array design and the maximum stimulation rates vary across manufacturers. Each manufacturer is attempting to create the optimum conditions necessary for approximating the acoustic properties of the original sound energy.

Regardless of the device implanted, the ultimate outcome of the cochlear implant is dependent upon many variables unique to each individual (Cohen, Labadie, Dietrich & Haynes, 2004; Knutson, Murray, Husarek, Westerhouse, Woodworth, Gantz, et al., 1998; Zwolan, Kileny & Telian, 1996). The U.S. Food and Drug Administration (2004) includes the following as factors which will influence the outcome of cochlear implantation: age at onset of deafness, length of deafness, age at time of cochlear implantation, length of implant use, quality of support, and integrity of remaining neural

structures. Although each of these factors is significant, age at onset of deafness has substantial importance for this project and is discussed further in the next section.

## II. Post-Lingually Deafened Adults

There are approximately three quarters to a million people over the age of 2 years in the United States with hearing loss of 70 decibels or greater in their better ear (Aguayo & Coady, 2001; Blanchfield, Feldman, Dunbar & Gardner, 2001). Hearing loss of this magnitude is described as severe to profound. When people lose their hearing before learning language, or are born with severe to profound hearing loss, their hearing loss is described as “pre-lingual” (Cooper, 1991). Many people with pre-lingual deafness use American Sign Language (ASL) to communicate (English, 2002). The American Deaf Community has emerged from a shared cultural experience based upon a shared language (ASL). Children who lose their hearing before speech and language mastery occurs are considered “peri-lingual” (Cooper, 1991). In contrast, when people lose their hearing after having mastered speech and language, their hearing loss is described as “post-lingual” (Cooper, 1991). Close to 75% of people with severe to profound hearing loss are considered post-lingually deafened adults (Aguayo & Coady, 2001; Cooper, 1991).

Post-lingually deafened adults typically do not consider themselves part of the Deaf community, nor do they use sign language for communication (Herbst, 2000; Kerr & Cowie, 1997; Luey, 1994; Lutman & Marshall, 1997; Rosen, 1979). In addition, not all post-lingually deafened adults receive useful benefit from hearing aids, defined as scoring 50% or better on aided sentence recognition tests in the ear to be implanted (Cochlear Limited, 2005; Cohen, Labadie, Dietrich & Haynes, 2004; Labadie, Carrasco, Gilmer & Pillsbury, 2000; UK Cochlear Implant Study Group, 2004). As a result, many

post-lingually deafened adults find themselves struggling to communicate successfully (Luey, 1994; Lutman & Marshall, 1997; Mulrow, Aguilar, Endicott, Velez, Tuley, Charlip, et al., 1990; Rosen, 1979). The struggle to communicate has a direct impact on their quality of life (Aguayo & Coady, 2001; Cohen, Labadie, Dietrich & Haynes, 2004; Kerr & Cowie, 1997).

### III. Quality of Life (QoL)

The concept of “quality of life” (QoL) has been in evidence in the Western world since at least ancient Greece (Bowling, 1999; Fayers & Machin, 2000). Fayers and Machin (2000) relate Aristotle’s (384-322 BC) observations on the changeable nature of the concept of QoL:

Both the multitude and persons of refinement...conceive ‘the good life’ or ‘doing well’ to be the same thing as ‘being happy’. But what constitutes happiness is a matter of dispute...some say one thing and some another, indeed very often the same man says different things at different times: when he falls sick he thinks health is happiness, when he is poor, wealth.  
(p. 5)

In modern times, QoL has been measured in nearly all facets of life ranging from urban planning to commercial product satisfaction (Bowling, 1999; Fayers & Machin, 2000). QoL has been described conceptually as subjective, multi-dimensional and inseparable from the cultural, social and environmental context of the individual (Bowling, 1999; Fayers & Machin, 2000; World Health Organization Quality of Life Group, 1998). A simplistic definition of QoL is “the ability to lead a normal life”

(Bowling, 1999, p. 2). A more complex definition of QoL, as agreed upon by the World Health Organization Quality of Life Group (1998) follows:

An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment. (p.3)

Modern health-related QoL is but a narrower focus of overall QoL, however the phrase QoL is frequently used to convey health-related QoL (Bowling, 1999; Fayers & Machin, 2000; World Health Organization Quality of Life Group, 1998). Interest in health-related QoL has stemmed from people's experiences with chronic disease and the expensive, invasive, and often non-curing medical procedures used to treat chronic disease. Assessing QoL pre and post treatment is one way to document the impact of a disease or condition and the effect of any subsequent treatments. Information about expected QoL improvements can provide more inclusive informed consent decisions about possible treatment outcomes. In addition, medical procedures frequently involve the allocation of limited resources. Information about QoL improvements can shape resource allocation on the policy level, as well as, the clinical level.

#### IV. Post-lingual Deafness and QoL

Post-lingual deafness has a profound effect upon a person's QoL (Aguayo & Coady, 2001; English, 2002; Herbst, 2000; Kerr & Cowie, 1997; Labadie, Carrasco,



Gilmer & Pillsbury, 2000; Luey, 1994; Wexler, 1982). People who are deafened post-lingually frequently have no previous connection to the Deaf community (English, 2002). This leaves the person feeling “caught” between the hearing world and the Deaf community, truly belonging to neither. Although people with post-lingual deafness have hearing thresholds in common with people who are Deaf, they do not share a common language or culture. As Aguayo and Coady (2001) found, post-lingually deafened people must confront the loss of their self image, because Deafness is not their identity.

Not only is a person’s self image affected, but clearly the ability to communicate is dramatically affected, as well (Aguayo & Coady, 2001; Kerr & Cowie, 1997; Luey, 1994; Wexler, 1982). Many people who are deafened post-lingually find spontaneous communication to be nearly impossible (Kerr & Cowie, 1997). They feel left out of conversations because it is difficult to follow threads of spoken communication. Attempts to participate in conversations often result in social gaffes and inappropriate responses (Aguayo & Coady, 2001; Kerr & Cowie, 1997). Many people report that this makes them feel “stupid” and embarrassed (Aguayo & Coady, 2001; Herbst, 2000; Kerr & Cowie, 1997).

Unfortunately, over time, many people who have been deafened post-lingually withdraw socially (Aguayo & Coady, 2001; English, 2002; Herbst, 2000; Kerr & Cowie, 1997; Luey, 1994; Wexler, 1982). Communication proves too difficult and stressful, often leading to social withdrawal. People with post-lingual deafness have reported the following feelings: isolation, loneliness, self doubt, inadequacy; anxiety, anger; frustration, panic, denial, vulnerability, bitterness, loss of confidence and boredom. Furthermore, the most frequently reported experience of people with post-lingual

deafness is depression. Herbst (2000) found that people who have been post-lingually deafened are four times more likely to suffer from depression than the general population.

Depression can have a pervasive influence on the QoL of people who have been post-lingually deafened (Aguayo & Coady, 2001; Herbst, 2000). Aguayo and Coady (2001) found that post-lingually deafened adults have higher divorce rates than the general population. This may be due to the increased dependence of the person with post-lingual deafness upon significant others, spouses and family members, who experience stress. Wexler (1982) found that several people reported feelings of being a burden. In addition, several people with post-lingual deafness reported feeling excluded from and punished by their families (Aguayo & Coady, 2001).

Not only do individual families experience difficulty coping with post-lingual deafness, but society as a whole, does not have much understanding of this phenomenon (Herbst, 2000; Rosen, 1979). Rosen (1979) reported that attitude surveys showed a lack of public awareness of, and lack of sympathy for, people with hearing loss. Herbst (2000) also found a lack of societal empathy for people with hearing loss. Furthermore, issues relating to negative attitudes towards deafness and links to ageism were prevalent. Jokes about hearing loss are the third most frequently joked about physical disability (Herbst, 2000).

## V. The Importance of Assessing QoL

Assessing QoL with post-lingually deafened adults has many advantages (Bowling, 1995; Fayers & Machin, 2000; Knutson, Murray, Husarek, Westerhouse, Woodworth, Gantz, et al., 1998; National Association of the Deaf, 2000; National Institutes of Health, 1995; United Kingdom Cochlear Implant Study Group, 2004; World

Health Organization Quality of Life Group, 1998; Zwolan, Kileny & Telian, 1996). Bowling (1995) reports that QoL is assessed in healthcare because people are living longer and their expectations about QoL as they age are increasing. As noted earlier, for post-lingually deafened adults, this can mean the ability to continue to actively participate in their hearing worlds (Aguayo & Coady, 2001; Herbst, 2000). In addition, there is increased pressure to make cost-effective healthcare decisions (Bowling, 1995; National Institutes of Health, 1995). People want to know how effective their proposed healthcare treatments will be. Assessing QoL can provide important information to guide the informed consent process for invasive procedures, such as cochlear implants (Bowling, 1995; Fayers & Machin, 2000; National Association of the Deaf, 2000).

Furthermore, Fayers and Machin (2000) report that many current healthcare treatments fail to cure, and that the treatments may provide limited benefits with unpleasant side effects. There is general consensus that cochlear implants do not cure deafness; they are a treatment option for deafness (National Association of the Deaf, 2000; National Institutes of Health, 1995; U.S. Food and Drug Administration, 2004). Hence, Fayers and Machin (2000) make the point that assessing QoL provides information about quantifying whether healthcare treatments that fail to cure are worth the inherent risks and side effects associated with them. This is especially relevant when considering cochlear implants because they are an elective, non-life saving, yet invasive procedure which, as noted above, has highly variable results from person to person (Knutson, Murray, Husarek, Westerhouse, Woodworth, Gantz, et al. (1998).

In addition, several organizations' consensus statements call for research to be conducted on cochlear implants and their effect on QoL (National Association of the

Deaf, 2000; National Institutes of Health, 1995). The National Institutes of Health Consensus Statement (1995) asserted that cochlear implant QoL research is needed to provide: (a) data on the long-term psychological and social effects of cochlear implants, (b) adequate assessment tools of non-speech, QoL benefit, and (c) cost-utility information. Likewise, the National Association of the Deaf Consensus Statement (2000) asserted that QoL research on cochlear implants will help people to develop realistic and appropriate expectations, as well as, provide data on the psychological, social and emotional adjustments to cochlear implants.

Another advantage of assessing cochlear implant QoL is that it provides an additional type of outcome measure rather than relying on post-implant audiometric and speech scores alone (Knutson, Murray, Husarek, Westerhouse, Woodworth, Gantz, et al., 1998; United Kingdom Cochlear Implant Study Group, 2004; Zwolan, Kileny & Telian, 1996). For example, eleven pre-lingually deafened people reported an improved QoL, after receiving a cochlear implant, even though their speech scores did not increase significantly (Zwolan, Kileny & Telian, 1996). In addition, English (2002) describes how the restoration of environmental sounds to post-lingually deafened adults can alleviate anxiety and depression by re-connecting them to the hearing world. This benefit results even when speech scores have not increased dramatically, revealing that functional speech scores alone do not provide a complete description of cochlear implant benefits (Zwolan, Kileny & Telian, 1996).

In order to understand the complete scope of how cochlear implants can provide benefit, it is important to consider the many roles of audition. Audition occurs on several levels, including primitive, warning and symbolic (English, 2002). Primitive audition

involves the ability to perceive and respond to environmental sounds, both consciously and unconsciously. Warning audition allows a person to perceive and respond to environmental sounds on a safety basis, while symbolic audition involves the ability to use hearing for the purpose of communication. Assessing QoL with post-lingually deafened adults provides a platform for evaluating changes on all levels of audition.

Finally, in many healthcare systems globally, cochlear implants are a limited resource and are allocated on a basis of highest expected outcome (Hawthorne & Hogan, 2002; Karinen, Sorri, Valimaa, Huttunen & Lopponen, 2001; Krabbe, Hinderink & Broek, 2000; Lehoux & Blume, 2000; United Kingdom Cochlear Implant Study Group, 2004). In these healthcare systems especially, it is critical that all aspects of cochlear implant benefit be considered when establishing criterion guidelines for who will receive cochlear implants. As a result, many of the earliest standardized QoL assessment tools were developed outside of the United States (Carter & Hailey, 1999; Gill, 1984; Hawthorne & Hogan, 2002; Hawthorne, Richardson & Day, 2001; Hinderink, Krabbe, and Broek, 2000; Karinen, Sorri, Valimaa, Huttunen & Lopponen, 2001).

## VI. How QoL is Assessed

Clinically, there are two broad approaches used to assess the QoL of post-lingually deafened adults with cochlear implants. These two approaches can be described as using standardized versus non-standardized assessment tools. Each approach has its own advantages and disadvantages (Fayers & Machin, 2000; Patten, 2002; Schiavetti & Metz, 2002; Smith, 2002).

An advantage of using standardized assessment tools is that the tools are more reliable, thus providing more repeatable and consistent results than non-standardized

assessment tools (Patten, 2002; Smith, 2002). The standardization process involves many steps such as piloting of the assessment tool with smaller samples, developing administration protocols, providing scoring instructions and finally, normative data to assist with plotting and interpreting scores (Fayers & Machin, 2002). These steps allow responses to standardized assessment tools to be compared across samples. The disadvantage of standardized assessment tools is that this is a labor and resource intensive process that requires relatively large subject samples. Although the clinical population of post-lingually deafened adults is few in number, several standardized assessment tools have been used to assess their QoL. These include: the Mark III Health Utilities Index, the Glasgow Health Status Inventory, the Glasgow Benefit Inventory, the Nijmegen Cochlear Implant Questionnaire, the Patient Quality of Life Form, the Nottingham Health Profile, Minnesota Multiphasic Personality Inventory, the Beck Depression Inventory, the Revised UCLA Loneliness Scale; the Social Avoidance and Distress Scale, the Rathus Assertiveness Scale and the Dyadic Adjustment Scale (Hawthorne & Hogan, 2002; Hinderink, Krabbe, Broek, 2000; Karinen, Sorri, Valimaa, Huttunen & Lopponen, 2001; Knutson, Murray, Husarek, Westerhouse, Woodworth, Gantz, et al., 1998; Spitzer, Kessler & Bromberg, 1992; United Kingdom Cochlear Implant Study Group, 2004). Only two of these (the Nijmegen Cochlear Implant Questionnaire and the Patient Quality of Life Form) are specific to the QoL issues of cochlear implants.

In contrast, there are many more non-standardized QoL assessment tools used clinically with post-lingually deafened adults who have cochlear implants (Aguayo & Coady, 2001; Hogan, 1997; Hogan, Stewart & Giles, 2002; Horn, McMahon, McMahon, Lewis, Barker & Gherini, 1991; Kelsall, Shallop & Burnelli, 1995; Kerr & Cowie, 1997;

Lutman & Marshall, 1997; Shin, Fraysse, Deguine, Vales, Laborde, Bouccara, Sterkers & Uziel, 2000; Wexler, Berliner, Miller & Crary, 1982; Zwolan, Kileny & Telian, 1996). These non-standardized assessment tools, in the form of questionnaires and/or interviews, have been developed by individual cochlear implant centers, cochlear implant manufacturers or adapted from other QoL assessment tools, such as those used for hearing aid wearers. As mentioned above, the clinical population of post-lingually deafened adults is few in number and yields highly variable outcome results, thus making it difficult to standardize the QoL assessment tools. An advantage of using non-standardized QoL assessment tools is that they are usually shorter, requiring less time to administer and score (Patel, Veenstra & Patrick, 2003). However, the disadvantage of using non-standardized assessment tools is that the reliability, validity and responsiveness of the tools are unknown. As a result, the responses cannot be compared across samples with statistical significance (Fayers & Machin, 2002).

Another benefit of using a non-standardized QoL assessment tool is that it can be tailored to the specific issues of post-lingually deafened adults using cochlear implants as a population, as well as, to each individual (Patel, Veenstra & Patrick, 2003; Hogan, 1997). For example, a series of open-ended interview questions can be used successfully to assess QoL, or an individual can be asked to list five specific QoL areas targeted for improvement (Patel, Veenstra & Patrick, 2003). Whether the assessment tools are standardized or non-standardized, an increasing amount of research is available demonstrating that cochlear implants generally have a positive effect on the QoL of post-lingually deafened adults (Hogan, Stewart & Giles, 2002; Knutson, Murray, Husarek,

Westerhouse, Woodworth, Gantz, et al., 1998; United Kingdom Cochlear Implant Study Group, 2004).

## VII. How Cochlear Implants Affect QoL

George Bernard Shaw (1900) is noted to have said, “Courage consists in the readiness to sacrifice happiness for an intenser quality of life” (Fayers & Machin, 2000, p. 5). To date, roughly 80,000 people worldwide have demonstrated a willingness and courage to undergo the risks and expenses of surgery and rehabilitation in anticipation of an improved QoL post- cochlear implant (Advanced Bionics Corporation, 2005; Cochlear Limited, 2005; Med-El Corporation, 2005; U.S. Food and Drug Administration; 2004).

Numerous aspects of improved QoL following cochlear implantation have been reported by researchers using standardized QoL assessment tools. For example, researchers using the Nijmegen Cochlear Implant Questionnaire have reported an increase in overall QoL as well as, physical, psychological, emotional and social functioning (Cohen, Labadie, Dietrich & Haynes, 2004; Hinderink, Krabbe, Broek, 2000; Krabbe, Hinderink, Broek, 2000). Researchers using the Patient Quality of Life Form have found an increase in overall QoL accompanied by an increased ability to spontaneously communicate and a decrease in anxiety and depression (Maillet, Tyler & Jordan, 1995; Mo, Harris & Lindbaek, 2004; Spitzer, Kessler & Bromberg, 1992). Additionally, results from studies using standardized psychological assessment tools have found an increase in self esteem, social interaction, assertiveness and marital happiness (Alpin, 1993; Harris, Anderson & Novak, 1995; Knutson, Murray, Husarek, Westerhouse, Woodworth, Gantz, et al., 1998).



Likewise, researchers using non-standardized QoL assessment tools have also reported multiple areas of QoL improvements for post-lingually deafened adults using cochlear implants. For instance, researchers using non-standardized questionnaires have reported increases in QoL relative to social life, confidence, telephone use, family life, and satisfaction with own voice (Djalilian, Smith, King & Levine, 2002; Faber & Grontved, 2000; Horn, McMahon, McMahon, Lewis, Barker & Gherini, 1991; Kelsall, Shalloo & Burnelli, 1995). Researchers using interview formats have reported increases in social confidence, self esteem, interpersonal, social, and employment gains (Hogan, Stewart & Giles, 2002; Hogan, 1997). One particularly poignant anecdote involving a 70 year old lady with multiple co-morbid conditions, including blindness and previous lung cancer, is reported by Labadie, Carrasco, Gilmer and Pillsbury (2002) as follows:

After successful implantation she was emotionally overcome with excitement. This represented the first time that she was actively able to participate in decisions regarding her healthcare. Although recurrent lung cancer with metastases to the brain ultimately developed, the cochlear implantation allowed her to communicate easily with doctors and family members as she was making decisions regarding the end of her life. (p. 423)

#### VIII. How QoL Assessment Can Be Helpful Clinically

Assessing QoL with post-lingually deafened adults can be helpful clinically by assisting with the counseling process both pre- and post-implant (Fayers & Machin, 2000; McKenna, 1991; Patel, Veenstra & Patrick, 2003; Ruta, Garratt, Leng, Russell & MacDonald, 1994). Pre-implant, the counseling process includes working with post-lingually deafened people to establish realistic expectations and achieve informed

consent. For example, McKenna (1991) asserts that people with post-lingual deafness are often depressed and it is critical to help them to establish realistic expectations about the cochlear implant experience. As mentioned above, cochlear implants are not cures for deafness, nor will cochlear implants resolve all relationship issues. People who are experiencing difficulties within their marriages and families may hope that post-implant all of their troubles will disappear (McKenna, 1991). Knutson, et al (1994) did find that many post-lingually deafened adults using cochlear implants reported an increase in their marital happiness, although, it took three years or more for this increase to occur. Helping people to establish realistic expectations is an important part of the informed consent process. Data generated by QoL research using standardized assessment tools may be shared with post-lingually deafened adults to help guide the informed consent process by sharing other's experiences.

Additionally, patient generated assessment tools have become an increasingly popular way of helping people to establish realistic expectations (Patel, Veenstra & Patrick, 2003; Ruta, Garratt, Leng, Russell & MacDonald, 1994). One method involves having the individual list five specific QoL areas that are targeted for expected improvement post cochlear implant. This process encourages the post-lingually deafened adult to thoroughly think about his/her motivations, hopes, and expectations and it provides the audiologist with personalized information rather than generic QoL data that may be obtained from a standardized assessment tool. As Fayers and Machin (2000) assert, people want to be active participants in their healthcare and are moving away from the model where the healthcare provider knows all. However, the healthcare provider, or

audiologist, must monitor this involvement to ensure that unrealistic expectations are addressed pre-implant (McKenna, 1991).

Another way in which assessing QoL can be helpful clinically is to track post-lingually deafened adults' progress through the post-cochlear implant rehabilitation process (Fayers & Machin, 2000; McKenna, 1991; Patel, Veenstra & Patrick, 2003). Using the five patient generated QoL goals as a benchmark, progress can be documented and shared with people as a way of providing encouragement and validation. In addition, if people surpass their initial goals and set new ones, the experience of having met the original goals will have been documented. In contrast, using standardized QoL assessment tools can serve to facilitate communication on a variety of QoL issues that may not be initiated by individual post-lingually deafened adults (Fayers & Machin, 2000). This process can serve to further the discussion on ways to maximize the use of the cochlear implant such as modifying the mapping strategy, creating additional listening programs, and encouraging people to try new listening experiences as they adjust to their cochlear implant (McKenna, 1991). In addition, using standardized QoL assessment tools with each post-lingually deafened adult provides a way to statistically compare meaningful changes in QoL between people to identify trends that may potentially be helpful to others.

## IX. How QoL Assessment Can Be Helpful with Strategic

### Planning for Cochlear Implant Centers.

Not only can assessing QoL be helpful clinically, but it can also be helpful with strategic planning for cochlear implant centers. Ginter, Swayne and Duncan (2002) define strategic planning as the process of positioning healthcare organizations to take

advantage of emerging opportunities while avoiding external threats. The US healthcare market is ever-changing. Strategic planning provides a framework for thriving through several trends affecting cochlear implant centers, such as an aging population, an increased average life span, emerging technologies, the growing importance of market niche services and strategies, mandates for clinical protocols and an increased emphasis on both cost containment and outcome measures (Ginter, Swayne & Duncan, 2002).

While cost containment and outcome measures have been standard policy for decades in “government pay” healthcare societies where expensive treatments are rationed, these are newer concepts in the US “health insurance pay” culture (Bichey, Hoversland, Wynne, & Miyamoto, 2002; UKCI Study Group, 2004). Several researchers have described the disparity between the cost of cochlear implants in the US and the reimbursement rates provided through Medicare, Medicaid and private fee-for-service health insurance (Bichey, Hoversland, Wynne, & Miyamoto, 2002; Blanchfield, Feldman, Dunbar, & Gardner, 2001; Garber, Ridgely, Bradley & Chin, 2002). A very cogent external threat to cochlear implant centers is the fact that providing these services results in a loss of revenue for the healthcare organization. Garber et al. (2002) found that physicians and healthcare organizations were willing to provide cochlear implant services, despite financial sacrifices, due to a sense of professional responsibility to patients, personal satisfaction, and the desire to be at the forefront of technology. Unfortunately, these altruistic motives are often in conflict with the economic realities facing US healthcare organizations.

One way that cochlear implant centers can prepare for such a conflict is to track the efficacy of treatments using QoL assessment data. As mentioned earlier in the

Literature Review, the outcomes of cochlear implants, especially as measured by audiological scores alone, are extremely variable among individuals. A more consistent outcome measure among post-lingually deafened adults is obtained by comparing the health utility of individuals pre- and post- cochlear implant (Cheng & Niparko, 1999). Health utility refers to the amount of improved QoL weighted by life expectancy after the treatment. Health utility is expressed in Quality Adjusted Life Years (QALY). In the US, healthcare treatments with a QALY of \$25K or less are considered acceptable and cost-effective by third party payors. Cheng and Niparko's (1999) meta-analysis reviewed seven research studies involving a total of 511 post-lingually deafened adults and cochlear implant cost effectiveness. The result of their meta-analysis was that, on average, cochlear implants in post-lingually deafened adults have a QALY of \$12, 787. This figure is well within the acceptable range. Whether tracking efficacy as part of a research study or simply as a way to document an individual's progress, assessing QoL can be part of a prudent addition to a cochlear implant center's strategic planning protocol.

#### Purpose of Study

The purpose of this qualitative research study was to explore the topics of QoL assessment, post-lingual deafness and cochlear implant centers on the East Coast of the US. In light of an increasing body of international and domestic research on QoL, cochlear implants and efficacy, it is unknown to what extent this information was being used in domestic clinical practice.

## Methodology

A qualitative research design was used to explore the use of quality of life (QoL) assessment tools with post-lingually deafened adult cochlear implant patients. A survey was developed and distributed to clinical service providers at 20 different cochlear implant centers serving post-lingually deafened adults. The clinical service providers were the research participants. In addition, a follow up interview was conducted with the participants who identified themselves as assessing QoL. The resulting data were analyzed using descriptive statistics.

### *Survey Development*

A one-page questionnaire (see Appendix B) was developed and distributed as a way to efficiently collect specific background data from each of the research participants. For example, the questionnaire asked participants to provide information about topics such as what services their centers provided, how long they had been in the cochlear implant field, how many surgeries were performed annually, and whether the center was participating in a research study. In addition, the questionnaire asked if the center was assessing QoL with the post-lingually deafened adults being served.

A list of follow-up interview questions (see Appendix C) was also developed based upon the literature review findings. The follow-up interviews were conducted with the participants who identified themselves as assessing QoL. Topics addressed during the follow-up interviews included standardized and non-standardized QoL assessment tools, categories of QoL assessed, and use of QoL data for counseling, efficacy reporting, and research.

### *Research Participants*

The research participants consisted of clinical service providers at 20 different cochlear implant centers serving post-lingually deafened adults. The principal investigator chose to focus on centers found on the East coast due to geographic convenience. Twenty out of a possible 50 centers on the East coast, ranging from New York to Florida, were selected from the three cochlear implant manufacturer websites. One to three centers were selected per state. This was done in an effort to represent centers from all of the East coast states rather than just New York state, which has 17 cochlear implant centers. The website listings of cochlear implant centers were available to the public. Prior to data collection, the principal investigator telephoned each of the 20 cochlear implant centers to confirm contact names and addresses of the research participants.

### *Data Collection and Analysis*

Participation in this study involved two steps. Each participant was mailed a letter of introduction explaining the study (see Appendix D), a letter of informed consent (see Appendix E) and a questionnaire (see Appendix A). Each participant was asked to complete and return the enclosed informed consent and questionnaire. Completing and returning both the informed consent and questionnaire constituted Step one of participation in the study. See Figure 1 for more detail on each of these steps.

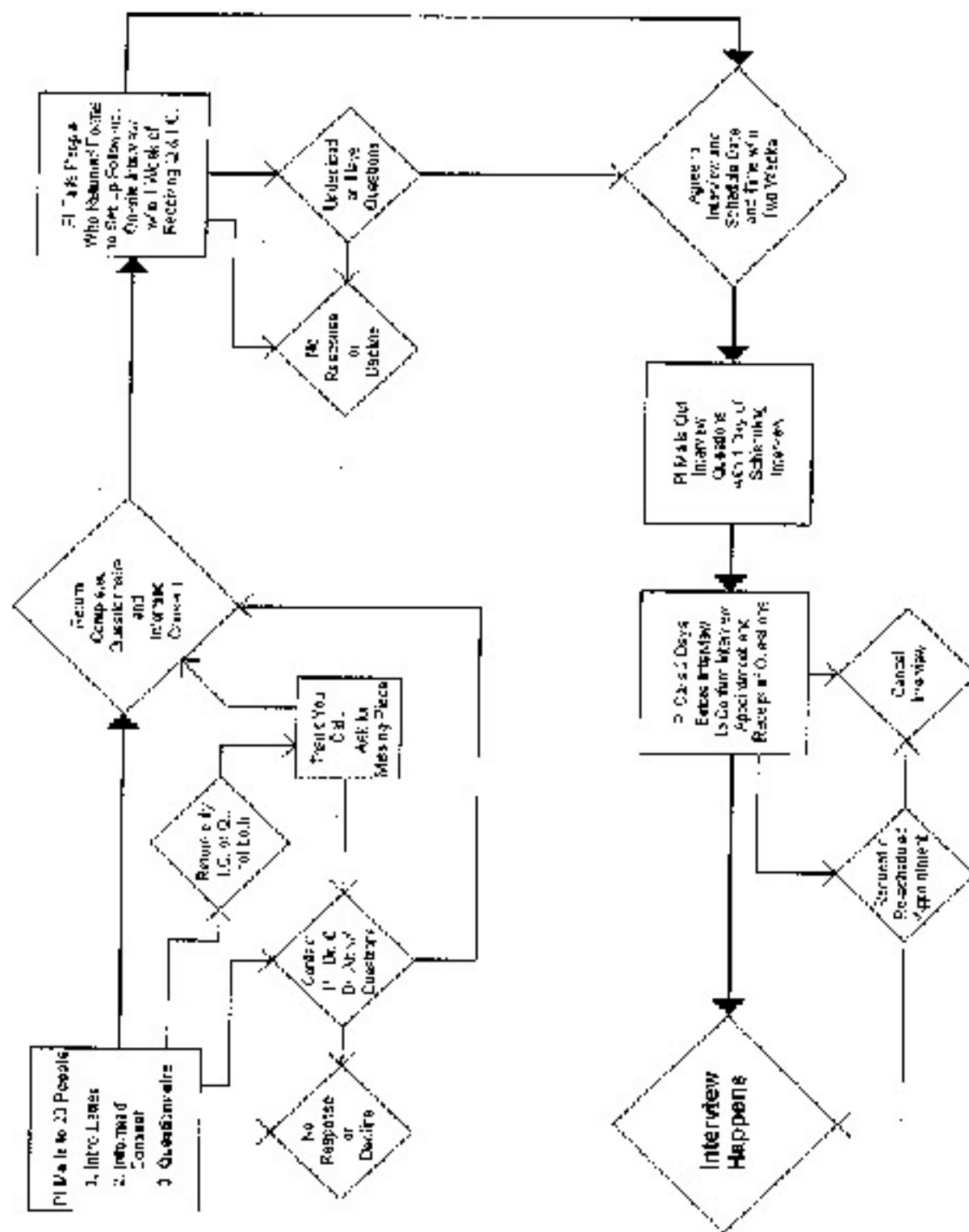
Step two of participation in the study involved a follow-up interview. Within one week of receipt of both the completed informed consent and the questionnaire, the principal investigator telephoned participants to set up the follow-up interview. It was

anticipated that five clinical service providers who had completed Step one of the study would agree to participate in the follow-up interview.

A copy of the interview questions (see Appendix C) was mailed to the participants within three days of scheduling the interview. Two days before the follow-up interview, the principal investigator called each participant to confirm the interview appointment and receipt of the interview questions.



Figure1 Flow Chart



For the participants who confirmed the interview appointment, the principal investigator and the participant either met face to face or spoke on the telephone for the follow-up interview at the scheduled appointment time. All of the follow-up interviews were completed via telephone, except one. This interview was completed in person due to geographic proximity. Completion of the follow-up interview constituted Step two of the study. This concluded the responsibilities of the participants.

There were no known risks, either physiological or psychological to the study participants. Several steps were taken to maintain the confidentiality of the study participants including not revealing the individual names of the centers or participants. Only the principal investigator and faculty sponsor knew what data came from which center. Each center was assigned a random four digit number and the listing of each center's number was kept in a secure place in the faculty sponsor's office.

The data were recorded by hand and entered into an Excel spreadsheet for tabulation and descriptive analysis. The data analysis consisted of looking for trends among the data of similarities or differences among the cochlear implant centers. Due to the small number of research participants, it was not appropriate to use higher level statistical analysis. In addition, it may not be appropriate to generalize the data from this study to the population of all cochlear implant centers.

## Results

### *Questionnaire Data*

Of the 20 centers polled, 10 clinical service providers returned both the signed Informed Consent Letter and the Questionnaire resulting in a 50 percent survey return

rate. Of these 10 participants, 6 clinical service providers reported that they assess QoL with post-lingually deafened adults. Table 1 displays the data collected from the questionnaires completed by these 6 research participants. The smallest cochlear implant center reported performing seven surgeries annually and the largest reported performing 130 surgeries annually. Four of the 6 centers reported that this was the same number of surgeries performed as in 2003. In addition, the newest cochlear implant center reported having performed surgeries for the past three years and the oldest center reported having performed surgeries over the past 19 years. The audiologists working in the centers have been in the cochlear implant field ranging from 2 years to 19 years. All but one audiologist has worked in the cochlear implant field six or fewer years.

Additional information displayed in Table 1 includes a listing of the cochlear implant services provided by each center. All 6 of the centers reported performing candidacy, pre-surgery, initial mapping and follow up services. In addition, all 6 centers reported being primarily funded by health insurance revenue. Only 1 center is currently participating in a research study, although 2 of the centers have been previously and 1 of the centers reported being in the development stage of a research study. Five of the 6 centers reported assessing QoL both pre- and post- implant, while one of the centers reported only assessing QoL pre-implant. None of the 6 centers reported being required by health insurance companies to document QoL data to receive payment for services.

Table 1

## Questionnaire Data From the 6 Centers Assessing QoL

<u>Question</u>	<u>Centers</u>					
	A	B	C	D	E	F
No. of Annual Surgeries?	12	20	130	40	7	35
More or less than last year?	more	more	same	same	same	same
Years of surgeries?	3	10	9	19	6	10
Years in CI field?	3	4.5	2	19	6	4
QoL assessed pre or post?	both	both	both	both	Pre only	both
Center in a study?	yes	no	no	no	no	no

*Follow-up Interview Data*

Figure 2 displays the methods used to assess QoL as reported by the 6 participants. These data were collected during the follow-up interviews. Specifically, 3 of the 6 research participants reported using an informal, patient-driven interview format as the only method of assessing QoL with post-lingually deafened adults. One of the 6 research participants reported using a combination of a standardized questionnaire and an informal, patient-driven interview as the method of assessing QoL. The standardized questionnaire used is the Patient Quality of Life Form, which was specifically designed

by the House Ear Institute to be used with cochlear implant patients. Two of the 6 research participants reported using a combination of a non-standardized questionnaire and an informal, patient-driven interview format to assess QoL. Both of the non-standardized questionnaires used at these centers were created either by, or with the help of, cochlear implant manufacturers (Advanced Bionics Corporation and Cochlear Limited). Finally, all 6 of the research participants reported informally assessing the post-lingually deafened adults' QoL through the experiences of their family/partners. This was accomplished using an interview format.

**Figure 2 Methods Used To Assess QoL**

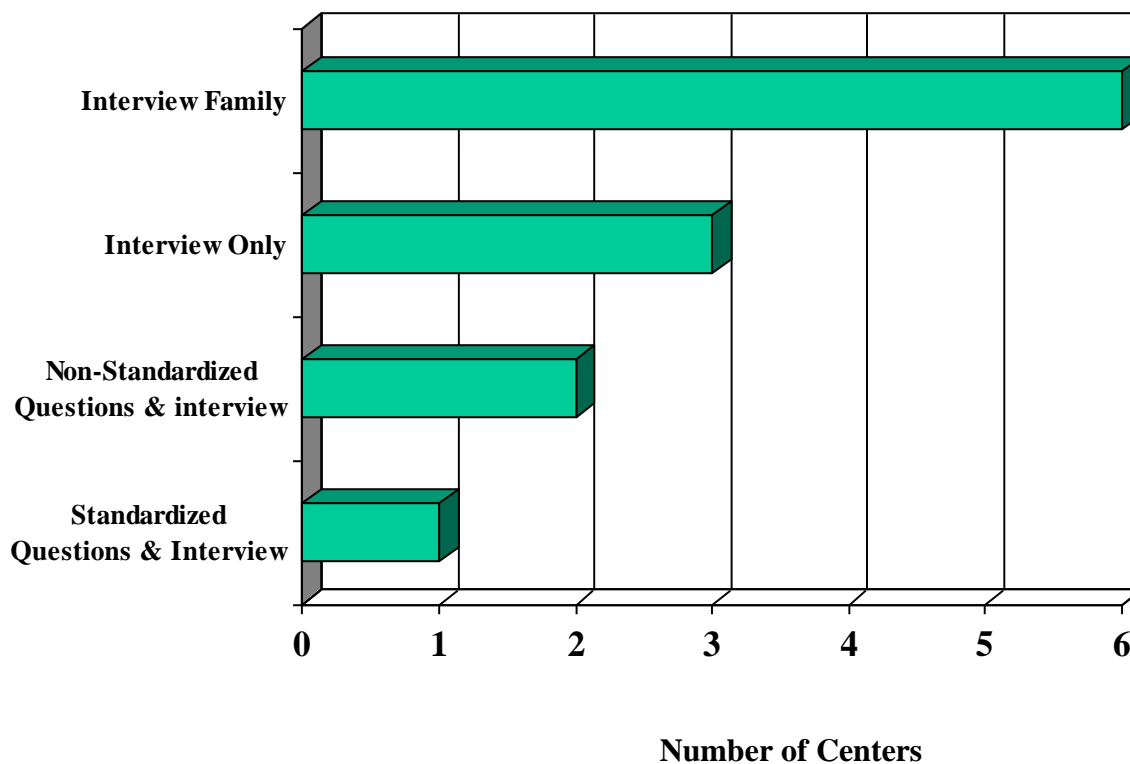


Table 2 displays which areas of QoL each center reported assessing. All 6 of the centers reported assessing the following QoL areas: music enjoyment, social opportunities, interpersonal relationships, feelings of personal safety, independence, ability to listen to media and ability to participate in group activities. Five of the 6 centers reported assessing ability to use the telephone, while 4 of the 6 centers reported assessing work opportunities/earnings potential and satisfaction with own voice. In addition, 3 of the 6 centers reported assessing educational opportunities and the ability to participate in sports/exercise. Furthermore, some of the centers included additional categories of QoL and thought they were important enough to mention. These additional categories included: performance in noisy situations, comfort telling others about their hearing loss, sensitivity to loud sounds and ability to understand speech in car.

Table 2

## Areas of QoL Assessed by 6 Cochlear Implant Centers

<u>Topic</u>	<u>Center</u>					
	A	B	C	D	E	F
Music enjoyment	+	+	+	+	+	+
Work opportunities/Earnings	+	0	+	+	0	+
Educational opportunities	+	0	+	+	0	0
Social opportunities	+	+	+	+	+	+
Interpersonal relationships	+	+	+	+	+	+
Feelings of personal safety	+	+	+	+	+	+
Ability to use telephone	+	+	+	+	+	0
Independence - communicate for self	+	+	+	+	+	+
Ability to listen to media – radio/tv	+	+	+	+	+	+
Ability to participate in sports/exercise	+	+	+	0	0	0
Ability to participate in group activities	+	+	+	+	+	+
Satisfaction with own voice	+	+	+	+	0	0

Figure 3 displays how the 6 research participants reported using the QoL data. For instance, 4 of the 6 research participants specifically mentioned, thus introducing the topic of QoL assessment as a way to help patients with establishing realistic expectations. During the follow up interview, each of these research participants stated that this was a primary use of the QoL data. Furthermore, 4 of the 6 research participants reported using the QoL data to guide the cochlear implant mapping process. Two of the research participants stated that the QoL data helped patients to focus more clearly on their listening experiences while using the cochlear implants and that this focus led to changes in the mapping. Finally, 3 of the 6 research participants reported using the QoL data as a way to document the patients' progress. For example, the pre-implant QoL assessment was reported as providing a baseline measure which was then compared and contrasted to post-implant QoL data. One of the research participants further stated that once pre-implant expectations had been met, the QoL data was used to help patients set new, realistic goals.



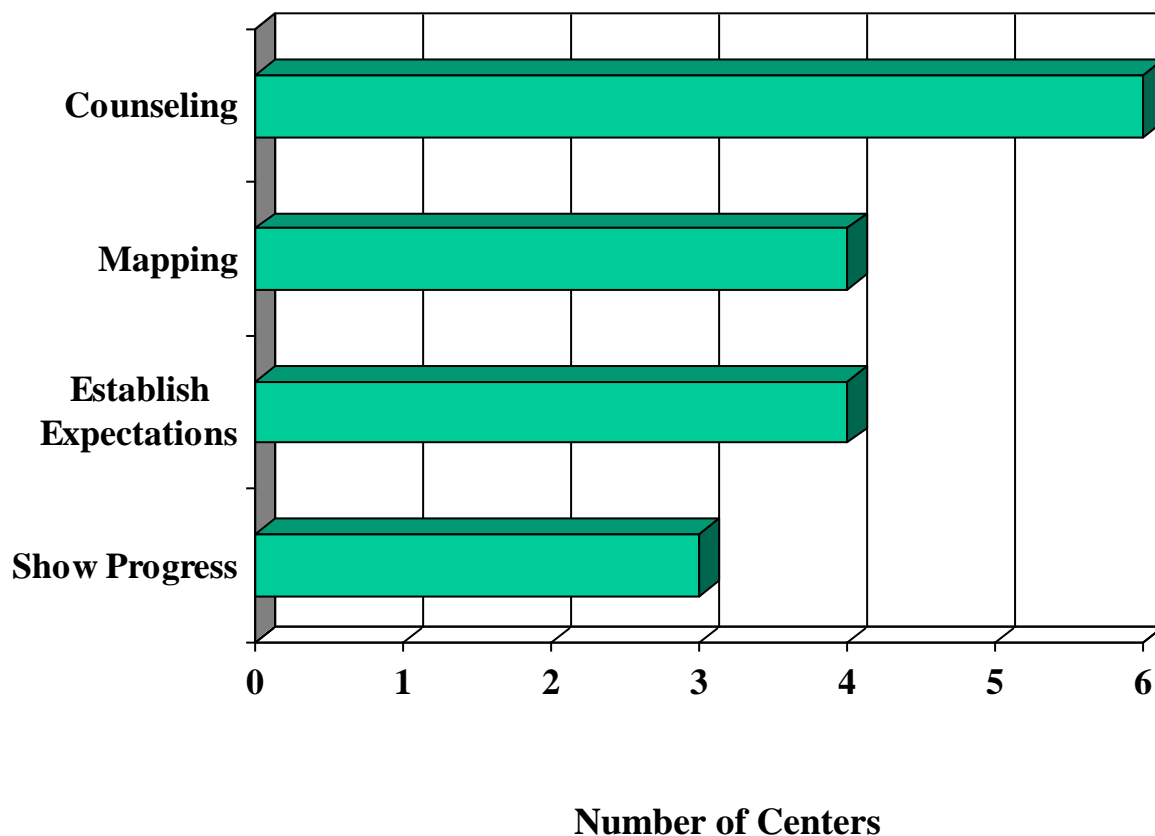
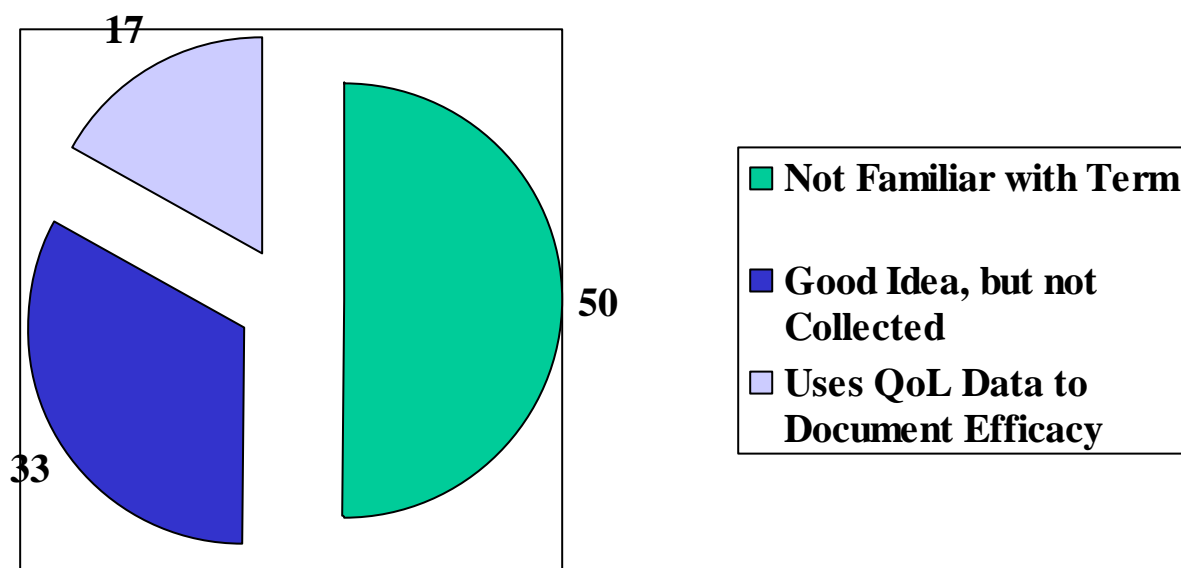
**Figure 3 How QoL Data is Used**

Figure 4 displays how participants responded to the follow-up interview questions related to reporting QoL data for efficacy documentation. One participant reported using the QoL data collected from post-lingually deafened adults as a way to document the efficacy of the cochlear implant center. This research participant stated, “You always want to depend on your hard numbers [audiological measurements] however, when hard numbers fail you, that’s when QoL data can be helpful”. For example, this research participant stated that QoL data can be used to help decide if bilateral implants would be

appropriate. In addition, QoL data can be used for justification of a cochlear implant in cases where the patient has borderline thresholds and receives some benefit from amplification. Two of the research participants stated that using QoL data to document efficacy is a good idea, however, it is not currently being done at their centers. One of these research participants had thought about possibly documenting efficacy in support of requesting funding through the institution's donor foundation. Finally, 3 of the 6 research participants were not familiar with the term "efficacy" nor did they know why or how this may be helpful.

**Figure 4 Efficacy Data**

This figure shows, by percentage of centers, how familiar the audiologist was with the term "efficacy" and how the efficacy data was used at that center.



In addition, 5 of the 6 research participants provided the data below during the follow-up interview about their experiences assessing QoL. The research participants from Centers A and D reported that assessing QoL is a good way to check on the effectiveness of the audiologist as a counselor. An example cited was using the QoL assessment experience to note if the patient had realistic expectations about the cochlear implant after being counseled by the audiologist. It was hoped that the counseling experience would help the patient to have realistic expectations and that if the patient persisted in having unrealistic expectations, then the effectiveness of the audiologist's counseling would be questioned. Both research participants did note, however, that some patients inherently had more realistic expectations than others. In addition, the research participant from Center D expressed concern about the inconsistency of pre-implant counseling that occurs among cochlear implant centers. This research participant went on further to state that it is suspected that many centers are not providing full pre-implant disclosure and possible inadequate post-implant follow-up care.

The research participants from three centers (B, C and F) also provided additional data during the follow-up interview. For instance, the research participant from Center B stated that assessing QoL with the patients' family/partner helps them to understand the entire process and to be more supportive of the implanted post-lingually deafened adult. Furthermore, this research participant reported that assessing QoL helps to focus the patient on the importance of social interaction. The three research participants mentioned above (Centers B, C and F) stated that assessing QoL can serve as a screening tool for feelings of isolation and possible depression. Furthermore, the research participant from

Center F stressed the importance of making an appropriate referral to a counseling professional in cases of suspected depression.

Finally, the research participant from Center C reported on using QoL data to pair pre-implant patients with implanted patients for a mentoring program. For example, implanted patients are asked if they would be interested in mentoring a pre-implant patient who may have questions. The QoL data is helpful with matching patients who have similar QoL concerns, such as living in a retirement home.

## Discussion

### *Caveats*

Due to the small number of both cochlear implant centers polled (20 out of approximately 50 found on the East coast) and research participants who identified themselves as assessing QoL (6), the results of this study may not be representative of the general cochlear implant center population. Although the data may be interesting, the results cannot be generalized to the larger population. A national survey was not feasible due to time, energy and financial constraints.

### *Interpretations*

It can be speculated that one reason why more centers did not respond to the survey was that perhaps the clinical service providers at these centers do not assess QoL with the post-lingually deafened adults served. Another reason why more centers may not have responded could be confusion related to the terminology addressed in this research study. For instance, both the terms “Quality of Life” and “efficacy” are not well understood nor consistently agreed upon (Fayers & Machin, 2000). Although international healthcare research and cutting-edge US research have addressed both of

these terms and their sequelae, only 3 of the participants knew what the term “efficacy” meant. Of these 3 only one participant was actively collecting and using efficacy data in support of the cochlear implant program. Three of the 6 participants were not familiar with the term “efficacy” and were unaware of how collecting these data could be helpful in documenting the benefits of cochlear implants and their programs. This lack of awareness suggested a gap in understanding the connection between the fact that providing cochlear implant services actually loses money for healthcare organizations and job security for clinical service providers. In an era of healthcare cost containment, it is logical and prudent to have as much data as possible to justify the existence of all healthcare services provided. This is especially true for specialty services such as cochlear implants where audiological data and outcome benefit may not be consistent from person to person.

These data also suggest that many of the participants in this research study were not aware of current international research in the cochlear implant field. Much of the QoL research relating to cochlear implants did not originate from the US. Furthermore, much of this research was not published in US publications. It would be unfortunate if helpful international research were not used in US cochlear implant centers due to lack of awareness.

There was also some confusion among the participants about how to define the term “Quality of Life” (QoL). This confusion was not unique to audiologists, it exists in many other healthcare disciplines, as well (Fayers & Machin, 2000). As mentioned in the Literature Review, other healthcare disciplines, such as cardiology and oncology, have used QoL data in support of evaluating the efficacy of treatments (Bichey, Hoversland,

Wynne, & Miyamoto, 2002). These disciplines also debate how to define QoL and subsequently how to assess QoL (Fayers & Machin, 2000). In this study, several participants were unsure if what they were doing was in fact assessing QoL. For example, 3 of the 6 participants were using an informal, patient-driven interview format during counseling and identified this as assessing QoL. If this protocol is considered assessing QoL, then are all clinical service providers who ask their cochlear implant patients questions, such as, “How are you doing?” assessing QoL? Perhaps many centers are following this protocol, but not identifying it as assessing QoL. However, when a patient-driven interview format is the only method used to assess QoL, there is no way to be certain which topics are and are not being addressed with each patient. In contrast, when a questionnaire format is used, at least there is consistency from patient to patient regarding the QoL topics being assessed. A questionnaire used before and after implantation also provides pre and post implant results which can be tracked. This leads to a further concern revealed by the data.

Several of the participants were not familiar with the terms “standardized” and “non-standardized” as they applied to the assessment tools. In particular, one participant reported not knowing the origins of the questionnaire being used to assess QoL. The participant stated, “I got it from one of the manufacturers, but I am not sure if it is standardized or not.” This lack of information about the assessment tool being used revealed that the participant was not aware of the responsibility of being an independent, educated professional. In addition, if the participant was not sure if the assessment tool was standardized or not, there was some concern about whether the tool was being administered properly, especially regarding scoring. Furthermore, it would be

inappropriate to compare results from a non-standardized assessment tool across populations. This would lead to a questionable validity of the results.

Another observation from the data was that 5 of the 6 centers were assessing QoL both pre- and post- implant, which is very thorough. One of the centers, however, was only assessing QoL pre-implant. When QoL is only assessed before the cochlear implant surgery, this suggests that any effects and or changes following the surgery and activation are not being measured. When asked why QoL was not assessed post-implant, the participant cited lack of time. Another interpretation of this protocol is that the main reason for assessing QoL at this center was to guide a person towards choosing a cochlear implant rather than using a hearing aid. As a result, this center really only assessed QoL with a hearing aid and not a cochlear implant because QoL was not assessed post-surgery. Again, this revealed the confusion that exists about what QoL is and how it is assessed.

#### *Call for Future Research/Future Trends*

It was striking that only one center was currently involved in a research study. The implication of this information was that clearly there is a need for more research in the field of audiology. Cochlear implants are still a relatively new technology compared to hearing aids and the profession could greatly benefit from independent research on QoL and the benefits of cochlear implants.

It would be interesting to see if such research would find a link between the quality of the follow up care provided and a greater perceived QoL benefit. There was no agreed-upon standard of care for cochlear implant services. Although the 6 participants reported providing the same services, each of the participants followed a different

standard of care in providing these services. Again, this is not unique to the profession of audiology. Many other healthcare professions were also concerned about the great variability in standards of care within their disciplines (Robinson, 1999). Evidence based medicine/practice (EBM/P) has been an emerging movement in both foreign and US healthcare cultures (ASHA, 2004; Mendelson & Carino, 2005; Robinson, 1999).

EBM/P is an approach to clinical treatment that relies upon a critical appraisal of research evidence in a systematic way (Robinson, 1999). This appraisal, in conjunction with clinical insight, results in published practice guidelines. The intended goal of the practice guidelines is to standardized quality care, help identify cost-effective strategies and curb unfounded practices (ASHA, 2004). Assessing QoL with post-lingually deafened adults can help to establish practice guidelines, as well as, be an effective way to document outcomes on an individual and center basis. However, Mendelson and Carino (2005) report that one barrier to the emergence of EBM/P is a lack of valid research to evaluate. This has been identified as an area of needed research in the cochlear implant field. With additional research, a future trend may be that health insurance companies require efficacy data and/or documentation that standards of care were followed before payment would be made. In this scenario, QoL data would be vital in documenting the effects of the treatment (cochlear implant).

The data suggested another trend as well. Five of the 6 participants have worked in the cochlear implant field 6 or fewer years. It would be noteworthy to investigate if this was a trend throughout cochlear implant centers nationwide. In this research study, it appeared that audiologists who were newer to the cochlear implant field reported assessing QoL. It was difficult to make any generalizations from this trend because it



could be that audiologists who have been working in the cochlear implant field longer than 6 years chose not to participate in this research study. It could also be that there are new centers opening and, as a result, there are more opportunities for audiologists who want to work with cochlear implant patients.

In summary, QoL assessment is emerging as another way to measure outcomes of individuals with cochlear implants. Assessing QoL can provide an enhanced experience for the patient, as well as, provide efficacy data for clinical service providers. Results of this study suggest the need for a standard protocol of assessing QoL with post-lingually deafened adults who choose cochlear implants.

## APPENDICES

## Appendix A: IRB Approval



Date: Friday, May 28, 2004

### NOTICE OF APPROVAL

TO: Nancy Hart DEPT: CSDS

**PROJECT TITLE:** *A Study of Cochlear Implant Centers and Quality of Life (QoL) Assessment with Post-Lingually Deafened Adults*

**SPONSORING AGENCY:**

**APPROVAL NUMBER:** 04-A035

The Institutional Review Board for the Protection of Human Participants has approved the project described above. Approval was based on the descriptive material and procedures you submitted for review. Should any changes be made in your procedures, or if you should encounter any new risks, reactions, injuries, or deaths of persons as participants, you must notify the Board.

A consent form: ☒ is ☐ is not required of each participant

Assent: ☐ is ☐ is not required of each participant

This protocol was first approved on: 28-May-2004

This research will be reviewed every year from the date of first approval.



*[Signature]*  
 Marcie Weinstein, Member  
 Towson University Institutional Review Board

## Appendix B: Questionnaire

Position/ Title \_\_\_\_\_ Profession \_\_\_\_\_  
 Years in the CI field \_\_\_\_\_ Length of time at this center \_\_\_\_\_

**Part I: Center Information (Center = Cochlear Implant Program)**

- This center provides the following services:  
     \_\_\_ candidacy                      initial mapping  
     \_\_\_ pre-surgery counseling    \_\_\_ aural rehab  
         re: expectations            \_\_\_ follow up  
     \_\_\_ other \_\_\_\_\_

- How long has this center been performing surgeries on post-lingually deafened adults?  
 \_\_\_\_\_

- Approximately how many surgeries are performed annually?  
 \_\_\_\_\_

- Is this more or less than were performed last year?  
 \_\_\_\_\_

- How many surgeons perform cochlear implantation for your patients?  
 \_\_\_\_\_

- Approximately how many surgeries does each doctor perform annually?  
 \_\_\_\_\_

- This center is primarily funded by:  
     \_\_\_ health insurance revenue  
     \_\_\_ center foundation funds  
     \_\_\_ other \_\_\_\_\_

- Approximately how many of your patients' surgeries are covered, at least partially, by health insurance?  
 \_\_\_\_\_

**Part II: Quality of Life (QoL)**

- Does this center assess Quality of Life (QoL)?

\_\_\_ Yes \_\_\_ No

- If yes, is QoL assessed  
     \_\_\_ pre-surgery    \_\_\_ post-surgery  
     \_\_\_ pre- and post- surgery

- What percentage of patients do you assess QoL with  
     pre-surgery                      post-surgery  
     pre- and post- surgery \_\_\_\_\_

- Do any health insurance companies require QoL data in support of payment?  
     \_\_\_ Yes \_\_\_ No

- Is this center currently involved in a CI research study w/ a QoL component? \_\_\_ Yes \_\_\_ No

- If yes, does the research protocol dictate components of your rehab? Please elaborate.  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## Appendix C: Follow-Up Interview Questions

### Follow-up Interview Questions

1. If this center is involved in a research study, please describe the research protocols you are following. May I please have a copy of the research protocol that addresses QoL?
2. Regardless of whether this center is involved in a research study, please describe how QoL is assessed.
3. Please describe any standardized QoL assessment tools you are using.
4. Please describe any non-standardized QoL assessment tools you are using. May I please have a copy of this assessment tool for my own research? Is this something I could share, making sure to give proper credit?
5. Where were the non-standardized QoL assessment tools created? this center? another center? cochlear implant manufacturer?
6. Please describe the time intervals at which QoL is assessed both pre- and post-surgery. Is there a different protocol for the research study vs. for non-participants?
7. Are you assessing QoL in a face-to-face interview format with patients? Are you using paper/pencil format? Please describe your experiences with each approach
8. If using paper/pencil format, do you give the QoL assessment tool to the patient in the waiting room or is it mailed to the patient's home? Please describe your experiences with each approach.
9. Are you assessing QoL re: any of these issues? Check all that apply:
  - ☐ music enjoyment
  - ☐ work opportunities/earnings
  - ☐ educational opportunities
  - ☐ social opportunities
  - ☐ interpersonal relationships - immediate family
  - ☐ feelings of personal safety
  - ☐ ability to use telephone
  - ☐ independence - make own appointments, reservations, communicate for self
  - ☐ ability to listen to media - radio/tv
  - ☐ ability to participate in sports/exercise
  - ☐ ability to participate in group activities - bridge club
  - ☐ satisfaction with own voice
  - ☐ other - write in please



10. Are the patients' families/friends assessed for their experiences of the patients' QoL? If so, please describe how this is achieved.
11. Is the QoL data collected used for counseling? mapping modification? reporting efficacy of this center's program? research? other? With whom is this data shared?
12. To what extent is QoL data helpful in counseling patients? Please elaborate.
13. To what extent is QoL data helpful in modifying mapping? Please elaborate.
14. To what extent is QoL data helpful in reporting the efficacy of your program? Please elaborate.
15. Is there something I haven't asked you that is important about the way QoL is assessed at this center?
16. I'd like to review my notes with you as a quality check to see if I've recorded everything accurately.

## Appendix D: Letter of Introduction

Cochlear Implant Super Center  
3000 Hearing Way  
Hair Cell, MD 2118

Date

Dear Ms./Mr. CI Clinical Service Provider:

I am conducting a research study for my doctoral project as a second year Au.D. student at Towson University. The purpose of this study is to explore the use of Quality of Life (QoL) assessment tools at cochlear implant centers serving post-lingually deafened adults. I would like to ask for your participation. It is anticipated that this study will be helpful in providing administrators of cochlear implant centers with an idea of how other centers are assessing QoL with post-lingually deafened adults.

Participation in this study involves 2 steps:

- Step 1 – complete and return both the 1 page questionnaire and Informed Consent letter.
- Step 2 – participate in a follow-up interview at your center lasting ~ 45 minutes. Interview will be scheduled at your convenience and questions will be mailed in advance.

Participation in the study is voluntary and all information collected will be kept strictly confidential.

Thank you in advance for your time and consideration. If you have any questions or comments, please e-mail me at [nancyshawhart@aol.com](mailto:nancyshawhart@aol.com), or you may contact my faculty sponsor, Brandt Culpepper, Ph.D., at [bculpepper@towson.edu](mailto:bculpepper@towson.edu)

Sincerely,

Nancy Shaw Hart  
Au.D. student

## Appendix E: Letter of Informed Consent

## LETTER OF INFORMED CONSENT

PRINCIPAL INVESTIGATOR: **Nancy Shaw Hart** E-MAIL: **nancyshawhart@aol.com**

### Purpose of the Study:

This study is designed to explore the use of Quality of Life (QoL) assessment tools at cochlear implant centers serving post-lingually deafened adults.

### Procedures:

Please complete the mailed one-page questionnaire and return it in the self-addressed stamped envelope provided (Step 1). Upon receipt of the completed and returned questionnaire, I will contact you to set up a follow-up on-site interview at your convenience (Step 2). The follow-up on-site interview will take approximately 45 minutes of your time. The questions for the follow-up on-site interview will be mailed to you in advance.

### Risks/Discomfort:

There are no known risks associated with participation in the study.

### Benefits:

It is anticipated that the resulting aggregate data will be helpful in providing clinical service providers at cochlear implant centers with an idea of how other centers are assessing QoL with post-lingually deafened adults. A summary of study results will be mailed to all participants who completed the informed consent and the questionnaire.

### Alternatives to Participation:

Participation in this study is voluntary. You are free to withdraw, discontinue participation, or not answer select questions at any time.

### Cost/Compensation:

Participation in this study will involve no costs to you. You will also receive no remuneration.

### Confidentiality:

All information collected during the study period will be kept strictly confidential. Recorded data will be classified through randomly assigned identification numbers. Any

publications or reports that appear as a result of this project will not include identifying information on any participant.

If you agree to join this study, please sign your name below.

\_\_\_\_\_ I have read and understood the information on this form.

\_\_\_\_\_  
Subject's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Principal Investigator

\_\_\_\_\_  
Date

If you have any questions regarding this study, please contact Dr. Brandt Culpepper at (410) 704-3617 or the Institutional Review Board Chairperson, Dr. Patricia Alt, Office of University Research Services, 8000 York Road, Towson University, Towson, Maryland 21252; phone (410) 704-2236.

## REFERENCES

- Advanced Bionics Corporation (n.d.) *Bionic ear overview*. Retrieved March 12, 2005, from <http://www.cochlearimplant.com/tour.asp>
- Alpin, D. Y. (1993). Psychological evaluation of adults in a cochlear implant program. *American Annals of the Deaf*, 138(5), 415-419.
- American Speech-Language-Hearing Association (2004). *Evidence-based practice: Practice guidelines*. Retrieved 3/5/2005 from [http://www.asha.org/members/slp/topics/ebp/evidence\\_guidelines.htm](http://www.asha.org/members/slp/topics/ebp/evidence_guidelines.htm)
- Aguayo, M. O., & Coady, N. F. (2001). The experience of deafened adults: Implications for rehabilitative services. *Health & Social Work*, 26(4), 269-276.
- Bichey, B. G., Hoversland, J. M., Wynne, M. K., & Miyamoto, R. T. (2002). Changes in quality of life and the cost-utility associated with cochlear implantation in patients with large vestibular aqueduct syndrome. *Otology & Neurology*, 23(3), 323-327.
- Blanchfield, B. B., Feldman, J. J., Dunbar, J. L., & Gardner, E. N. (2001). The severely to profoundly hearing-impaired population in the United States: Prevalence estimates and demographics. *Journal of the American Academy of Audiology*, 12(4), 183-189.
- Bowling, A. (1995). *Measuring disease: A review of disease-specific quality of life measurement scales* (2<sup>nd</sup> ed.). Buckingham: Open University Press.
- Buchman, C. A., & Fucci, M. J. (1999). Cochlear implants in the geriatric population: Benefits outweigh risks. *ENT: Ear, Nose and Throat Journal*, 78(7), 489-493.
- Carter, R., & Hailey, D. (1999). Economic evaluation of the cochlear implant. *International Journal of Technology Assessment in Health Care*, 15(3), 520-530.

- Cheng, A. K. & Niparko, J. K. (1999). Cost-utility of the cochlear implant in adults: A meta-analysis. *Archives of Otolaryngology – Head & Neck Surgery*, 125(11), 1214-1218.
- Cochlear Limited (n.d.) *What is a cochlear implant?*. Retrieved March 12, 2005 from <http://www.cochlearamericas.com/What/161.asp>
- Cohen, S.M., Labadie, R.F., Dietrich, M.S. & Haynes, D.S. (2004). Quality of life in hearing-impaired adults: The role of cochlear implants and hearing aids. *Otolaryngology Head and Neck Surgery*, 131(4), 413-422.
- Cooper, H. (1991). Selection of candidates for cochlear implantation: An overview. In H. Cooper (Ed.). *Cochlear implants: A practical guide* (pp. 92-100). San Diego: Singular.
- Djalilian, H. R., Smith, S. L., King, T. A., & Levine, S. C. (2002). Cochlear implantation in the elderly: Results and quality of life assessment. *Annals of Otology, Rhinology, and Laryngology*, 111(10), 890-896.
- English, K. (2002). Psychosocial aspects of hearing impairment and counseling basics. In R. Schow & M. Nerbonne (Eds.). *Introduction to audiologic rehabilitation* (pp. 225 – 246). Boston: Allyn & Bacon.
- Faber, C. E., & Grontved, A. M. (2000). Cochlear implantation and change in quality of life. *Acta Oto-Laryngologica*, 120(Suppl.543), 151-153.
- Fayers, P. & Machin, D. (2000). *Quality of life: Assessment, analysis and interpretation*. New York: John Wiley & Sons.



- Francis, H. W., Chee, N., Yeagle, J., Cheng, A., & Niparko, J. K. (2002). Impact of cochlear implants on the functional health status of older adults. *Laryngoscope*, 112(8 Pt.1), 1482-1488.
- Garber, S., Ridgely, M., Bradley, M. & Chin, K. (2002). Payment under public and private insurance and access to cochlear implants. *Archives of Otolaryngology – Head & Neck Surgery*, 128(10), 1145-1152.
- Gill, T. M., & Feinstein, A. R. (1994). A critical appraisal of the quality of quality of life measurements. *Journal of the American Medical Association*, 272, 619-626.
- Ginter, P., Swayne, L. & Duncan, W. (2002). *Strategic Management of Health Care Organizations*. Malden, MA: Blackwell.
- Gutman, V. (Ed.). (2002). *Ethics in Mental Health and Deafness*. Washington, D.C.: Gallaudet University.
- Harris, J. P., Anderson, J. P., & Novak, R. (1995). An outcomes study of cochlear implants in deaf patients: Audiologic, economic, and quality-of-life changes. *Archives of Otolaryngology - Head & Neck Surgery*, 121(4), 398-404.
- Hawthorne, G., & Hogan, A. (2002). Measuring disability-specific patient benefit in cochlear implant programs: Developing a short form of the Glasgow Health Status Inventory, the Hearing Participation Scale. *International Journal of Audiology*, 41(8), 535-544.
- Hawthorne, G., Hogan, A., Giles, E., Stewart, M., Kethel, L., White, K., et al. (2004). Evaluating the health-related quality of life effects of cochlear implants: A prospective study of an adult cochlear implant program. *International Journal of Audiology*, 43(4), 183-192.

- Hawthorne, G., Richardson, J., & Day, N. (2001). A comparison of the Assessment of Quality of Life (AQoL) with four other generic utility instruments. *The Finnish Medical Society Duodecim, Annals of Medicine*, 33, 358-370.
- Herbst, K. (2000). Acquired deafness. In P. Hindley & N. Kitson (Eds.). *Mental health and deafness* (pp.253-281). London: Whurr BOOK
- Higgins, K. M., Chen, J. M., Nedzelski, J. M., Shipp, D., B., & McIlmoyl, L. D. (2002). A matched-pair comparison of two cochlear implant systems. *Journal of Otolaryngology*, 31(2), 97-106.
- Hinderink, J. B., Krabbe, P. F., & van den Broek, P. (2000). Development and application of a health-related quality-of-life instrument for adults with cochlear implants: the Nijmegen Cochlear Implant Questionnaire. *Otolaryngology - Head & Neck Surgery*, 123(6), 756-765.
- Hogan, A. (1997). Implant outcomes: Towards a mixed methodology for evaluating the efficacy of adult cochlear implant programmes. *Disability and Rehabilitation*, 19(6), 235-242.
- Hogan, A., Hawthorne, G., Kethel, L, et al. (2001). Quality of life outcomes from adult cochlear implantation: A cross-sectional study. *Cochlear Implants International*, 2, 115-128.
- Hogan, A., Stewart, M., & Giles, E. (2002). It's a whole new ballgame! Employment experiences of people with cochlear implants. *Cochlear Implants International*, 3(1), 54-67.

- Horn, K., McMahon, N., McMahon, D., Lewis, J., Barker, M., & Gherini, S. (1991). Functional use of the Nucleus 22-channel cochlear implant in the elderly. *Laryngoscope*, 101, 284-288.
- Horsman, J., Furlong, W., Feeny, D. & Torrance, G. (2003, October 16). The Health Utilities Index (HUI): Concepts, measurement properties and applications. *Health and Quality of Life Outcomes*, 1:54. Retrieved February 27, 2005, from <http://www.hqlo.com/content/1/1/54>
- House, W. & Berliner, K. (1991). Cochlear implants: From idea to clinical practice. In H. Cooper (Ed.). *Cochlear implants: A practical guide* (pp. 9-33). San Diego: Singular.
- Karinen, P. J., Sorri, M. J., Valimaa, T. T., Huttunen, K. H., & Lopponen, H. J. (2001). Cochlear implant patients and quality of life. *Scandinavian Audiology*, 30(Suppl.52), 48-50.
- Kelsall, D., Shallop, J., & Burnelli, T. (1995). Cochlear implantation in the elderly. *The American Journal of Otology*, 16(5), 609-615.
- Kerr, P.C. & Cowie, R.I. (1997). Acquired deafness: A multi-dimensional experience. *The British Journal of Audiology*, 31, 177-188.
- Knutson, J. F., Murray, K. T., Husarek, S., Westerhouse, K., Woodworth, G., Gantz, B. J., et al. (1998). Psychological change over 54 months of cochlear implant use. *Ear and Hearing*, 19(3), 191-201.
- Krabbe, P., Hinderink, J., & Broek, P. (2000). The effect of cochlear implant use in postlingually deaf adults. *International Journal of Technology Assessment in Health Care*, 16, 864-873

- Labadie, R. F., Carrasco, V. N., Gilmer, C. H., Pillsbury, H. C. (2000). Cochlear implant performance in senior citizens. *Otolaryngology Head and Neck Surgery*, 123, 419-424.
- Lehoux, P. & Blume, S. (2000). Technology assessment and the sociopolitics of health technologies. *Journal of Health Politics, Policy and Law*, 25(6), 1083-1122.
- Luey, H. S. (1994). Sensory loss: A neglected issue in social work. *Journal of Gerontological Social Work*, 21(3/4), 213-223.
- Lutman, M.E. & Marshall, D.H. (1997). Self-rated hearing disability in candidates for cochlear implants. *British Journal of Audiology*, 31, 149-152.
- Maillet, C. J., Tyler, R.S., & Jordan, H. N. (1995). Change in the quality of life of adult cochlear implant patients. *Annals of Otology, Rhinology, and Laryngology*, 165 (Suppl), 31-48.
- McKenna, L. (1991). The assessment of psychological variables in cochlear implant patients. In H. Cooper (Ed.). *Cochlear implants: A practical guide* (pp. 125-145). San Diego: Singular.
- Med-El Corporation (n.d.) How a cochlear implant works. Retrieved March 12, 2005 from [http://www.medel.com/ENG/US/10\\_Understanding\\_CI/20\\_How\\_a\\_CI\\_works/09\\_0\\_how\\_c...](http://www.medel.com/ENG/US/10_Understanding_CI/20_How_a_CI_works/09_0_how_c...)
- Mendelson, D. & Carino, T. (2005). Evidence-based medicine in the United States – de rigueur or dream deferred? *Health Affairs*, 24(1), 133-136.

- Mo, B., Harris, S. & Lindbaek, M. (2004). Cochlear implants and health status: A comparison with other hearing-impaired patients. *Annals of Otolaryngology, Rhinology, and Laryngology*, 113(11), 914-921.
- Mulrow, C., Aguilar, C., Endicott, J., Velez, R., Tuley, M., Charlip, W. et al. (1990). Association between hearing impairment and the quality of life of elderly individuals. *Journal of the American Geriatrics Society*, 38, 45-50.
- National Association of the Deaf (NAD) (2000), Position statement on cochlear implants. Retrieved February 25, 2005 from <http://www.nad.org/infocenter/newsroom/positions/CochlearImplants.html>
- National Institutes of Health (NIH) (1995), Cochlear implants in adults and children: NIH consensus statement. Retrieved February 25, 2005 from [http://consensus.nih.gov/cons/100/100\\_statement.htm](http://consensus.nih.gov/cons/100/100_statement.htm)
- Patel, K.K., Veenstra, D.L., & Patrick, D.L. (2003). A review of selected patient-generated outcome measures and their application in clinical trials. *Value in Health: The Journal of the International Society for Pharmacoeconomics and Outcomes Research*, 6(5), 595-603.
- Patrick, D. L, & Deyo, R. A. (1989). Generic and disease-specific measures in assessing health status and quality of life. *Medical Care*, 27, S217-S232.
- Patten, M.L. (2002). *Understanding research methods* (3<sup>rd</sup> ed.). Los Angeles: Pyrczak.
- Robinson, K. (1999). Evidence-based medicine and its implications for audiological science. *British Journal of Audiology*, 33, 9-16.
- Rosen, J.K. (1979). Psychological and social aspects of the evaluation of acquired hearing impairment. *Audiology*, 18, 238-252.

- Ruta, D. A., Garratt, A. M., Leng, M., Russell, I. T., MacDonald, L. M. (1994). A new approach to the measurement of quality of life: The patient-generated index. *Medical Care*, 32, 1109-1126.
- Schiavetti, N. & Metz, D. (2002). *Evaluating research in communicative disorders* (4<sup>th</sup> ed.). Boston: Allyn and Bacon
- Shin, Y., Fraysse, B., Deguine, O., Vales, O., Laborde, M., Bouccara, D., et al. (2000). Benefits of cochlear implantation in elderly patients. *Otolaryngology - Head & Neck Surgery*, 122(4), 602-606.
- Smith, S.S. (2002). Validation of health status instruments. In *Measuring the Immeasurable? Proceedings of a Conference on Quality of Life in Deaf Children*, (pp. 21-31). The Ear Foundation, Nottingham, UK
- Spitzer, J., Kessler, M., & Bromberg, B. (1992). Longitudinal findings in quality of life and perception of handicap following cochlear implantation. *Seminars in Hearing*, 13(3), 260-270.
- UKCISG (UK Cochlear Implant Study Group). (2004). Criteria of candidacy for unilateral cochlear implantation in postlingually deafened adults I: Theory and measures of effectiveness. *Ear and Hearing*, 25(4), 310-335.
- U.S. Food and Drug Administration (2004). *What is a cochlear implant?* Retrieved March 12, 2005 from [www.fda.gov/cdrh/cochlear/whatare.html](http://www.fda.gov/cdrh/cochlear/whatare.html)
- Weinstein, B. (2000). *Geriatric audiology*. New York: Thieme.
- Wexler, M., & Miller, L., Berliner, K. & Crary, W. (1982). Psychological effects of cochlear implant: Patient and “index relative” perceptions. *Annals of Otology, Rhinology, & Laryngology, Supplement*, 91, 59-61.

Wyatt, J., Niparko, J. Rothman, M. (1996) Cost-utility of the multichannel cochlear implant in 258 profoundly deaf individuals. *Laryngoscope* 106, 816 – 821.

WHOQoL Group (1998). Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. Retrieved February 26, 2005 from [http://www.who.int/evidence/assessment-instruments/qol/documents/WHOQOL\\_BIBLIOGRAPHY.pdf](http://www.who.int/evidence/assessment-instruments/qol/documents/WHOQOL_BIBLIOGRAPHY.pdf)

Zwolan, T. A., Kileny, P. R., & Telian, S. A. (1996). Self-report of cochlear implant use and satisfaction by prelingually deafened adults. *Ear and Hearing*, 17(3), 198-210.

## CURRICULUM VITA

NAME: Nancy E. Shaw Hart

PERMANENT ADDRESS: 2609 Littlestown Pike, Westminster, Maryland, 21158

PROGRAM OF STUDY: Audiology

DEGREE AND DATE TO BE CONFERRED: Doctor of Audiology, December, 2005

Secondary Education: Western Maryland College, Westminster, Maryland, May, 1988  
Towson University, Towson, Maryland, December, 2005

<u>Collegiate institutions attended</u>	<u>Dates</u>	<u>Degree</u>	<u>Date of Degree</u>
Western Maryland College	1984-1988	B.A.	May, 1988
Towson University	1999-2005	Au.D.	December, 2005

Major: Audiology

Clinical Experience:

Summer 2002 – Aural Habilitation: Pediatric Cochlear Implant, Towson University Clinic  
 Summer 2002 – Adult Audiology Clinic, Towson University Clinic  
 Fall 2002 – Adult and Pediatric Audiology Clinic, Towson University Clinic  
 Spring 2003 – Adult and Pediatric Audiology Clinic, Towson University Clinic  
 Spring, Summer, Fall 2003 - Pediatric Cleft Palate Clinic (Audiology Services): Kernan  
 Rehabilitation Center  
 Spring 2004 – Pediatric Audiology Clinic, Frederick County Developmental Center  
 Summer 2004 – Adult Cochlear Implant Services, Greater Baltimore Medical Center  
 (GBMC) Cochlear Implant Program  
 Summer, Fall 2004 – Private Practice Audiology, Hearing Specialty Group  
 Externship 2005 – Private Practice Audiology, Hearing Specialty Group